
What Does the Research Say About Early Detection and Intervention for Children with Autism?

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Introduction

Parallel lines of research and clinical practice suggest that autism is difficult to detect in very young children, but that children who receive early intervention have improved long-term prognoses. This session will provide a research-based overview of selected early screening methods that hold promise for accurate detection (including the Ages and Stages Questionnaire: Social-Emotional Development or ASQ:SE, currently under study). A brief review of the empirical support for successful early intervention with autistic children is also featured.

Introduction

“Despite the recent intense focus on autism, it continues to be an art and science in rapid evolution...”

Introduction

All children on the autistic spectrum demonstrate the same core deficits, in (a) reciprocal social interactions, and (b) verbal and nonverbal communication, with (c) restricted and repetitive behaviors or interests (APA, 1994).

It is important to understand that these criteria refer to a *qualitative impairment* in reciprocal social interactions, and *not* to the absolute lack of social behaviors. The behaviors under this rubric range from total lack of awareness of another person, to eye contact which is present but not used to modulate social interactions.

Background Relevant to Screening

Examples relevant to ASQ:SE: Criterion A1b. *Failure to develop peer relationships appropriate to developmental level.* “A child may want ‘friends’ but usually does not understand the concept of the reciprocity and sharing of interests and ideas inherent in friendship. For example, they might refer to all classmates as ‘friends.’” One telling example is the child who says without compunction, “Oh, I have many, many, twenty-nine friends, but none of them like me.” **Criterion A1d.** *Lack of social or emotional reciprocity.* “Some children with autism show no interest in other children or adults, and tend to play alone by themselves away from others. **Criterion A2.** *Qualitative impairment in communication.* “Expressive language function across the autistic spectrum ranges from complete mutism to verbal fluency, although fluency is often accompanied by many semantic (word meaning) and verbal pragmatic (use of language to communicate) errors.”

Background Relevant to Screening

Since we currently have no biological marker for autism, screening must focus on behavior. Furthermore, in most cases, autism appears to have a gradual onset, often without clear evidence of sensorimotor impairment. Children with autism typically sit, crawl, and walk at the expected age. Many even produce a few words at developmentally appropriate times, although these words seldom develop into useful early language. Symptoms that may be present during infancy (a serious expression, increased irritability, sleep and eating difficulties, and placidity) are behaviors commonly seen in otherwise typically developing children.

Fascinating Research Related to Early Detection

Two lines of research are looking at how early autism can be identified through behavioral symptoms. London (2001) reported that the National Alliance of Autism Research has funded the “Baby Sibs” project led by Dr. Rebecca Landa. Siblings are at risk for autism at a rate almost 50 fold over other children, or approximately 10% to 20%. In a prospective study, she will assess the infant siblings of children with autism beginning at 14 months of age to determine whether symptoms can be reliably determined at that age. The other line of research is retrospective in nature...

Fascinating Research Related to Early Detection

Osterling & Dawson, 1994, using home videotapes of first birthday parties in infants with autism versus typical development, found that four behaviors correctly classified over 90% of the autistic and typical children. These behaviors, later replicated by Mars, Mauk, & Dowrick, 1998, were eye contact, orienting to name being called, pointing, and showing. A more recent study using the same methodology (Osterling & Dawson, 1999) found that these 1-year olds with autism could also be distinguished from 1-year olds with idiopathic mental retardation and those with typical development. Furthermore, these same behaviors distinguished these same infants with autism at 8 to 10 months from those with typical development.

Fascinating Research Related to Early Detection

Baranek (1999) also examined video of 9- to 12-month olds and found that a pattern of nine behaviors differentiated between autism, developmental disabilities, and typical development with 94% accuracy. The autistic pattern included greater problems with responsiveness to social stimuli (e.g., delayed responding to name; social touch aversion), as well as other nonsocial aspects of sensory responsiveness. Although the long-range stability and predictive utility of these findings remains to be seen, these results suggest that autism will eventually be reliably detected as early as 1 year of age, or even younger.

Age of Diagnosis and Other Screening Criteria

Although many clinicians are reluctant to diagnose autism at an early age, much of the recent research focuses on the manifest behaviors or behavioral deficits seen in very young children that may be precursors of autism. Autism can be reliably diagnosed by or before the age of 3 years. Recent studies have demonstrated that symptoms of autism are measurable by 18 months of age, and that these symptoms are stable from toddler through the preschool age. Furthermore, these studies have identified the main characteristics that differentiate autism from other developmental disorders in the 20-month to 36-month age range, ***characteristics that early screening tools need to target.***

Age of Diagnosis and Other Screening Criteria

These involve negative symptoms, or behavioral deficits, in the following areas: eye contact, orienting to one's name, joint attention behaviors such as pointing or showing, pretend play, imitation, nonverbal communication, and language development. There is some indication that socially directed emotional behavior may also differentiate the groups; neither sensory-perceptual nor positive symptoms such as repetitive behavior or behavioral outbursts appear to consistently differentiate between autistic and nonautistic groups early on.

Age of Diagnosis and Other Screening Criteria

Although neither researchers nor practitioners claim that the identification of one indicator, or even a cluster of indicators, warrants a diagnosis of autism in children under 2, the presence of these indicators provides the basis for early intervention. Unfortunately, when faced with parental stress and concerns, pediatricians and psychologists often overlook early, subtle signs. Most children with autism are not diagnosed until close to their third birthday, when language difficulties and behavioral differences become more apparent.

Screen, Probe, Evaluate...

Screening for autism calls for two different levels of investigation, each answering a different question. **Level 1** screening should be performed on all children and involves identifying children at risk for any type of atypical development. **Level 2** involves a more in-depth investigation of children already identified to be at risk for a developmental disorder, differentiates autism from other kinds of developmental difficulties, and includes evaluations by autism specialists aimed at determining the best means of intervention based on the child's profile of strengths and weaknesses.

Improving Routine Surveillance and Screening

A consensus panel has agreed that primary care providers must change their approach to well-child care, so as to perform proactive screening for developmental disorders. It has been estimated that almost 25% of children in any practice demonstrate developmental issues at some point; therefore, developmental screening must become an absolutely essential routine of each and every well-child visit throughout infancy, toddler, and preschool years, and even beyond early school-age if concerns are raised. Unfortunately, fewer than 30% of primary care providers conduct standardized screening tests (in the rigid manner for which they were intended) at well-child appointments (e.g., Rapin, 1995).

Improving Routine Surveillance and Screening

Additionally, the American Academy of Pediatrics is stressing the importance of developmental *surveillance* at every well-child visit: a flexible, continuous process that is broader than screening and includes eliciting and valuing parental concerns, specific probing regarding age-appropriate skills in each developmental domain, and skilled observations. ***The ASQ:SE is an excellent tool to facilitate this process.***

Valuing Parental Concerns and Input in the Screening and Surveillance Process

It is important to realize that parents are usually correct in their concerns about their child's development, a point that has been demonstrated in many studies (e.g., Glascoe, 1994, 1997, 1998). They may not be as accurate regarding the qualitative and quantitative parameters surrounding the developmental abnormality, but almost always, if there is a concern, there is indeed a problem in some aspect of the child's development. So, any developmental concern must be valued and further investigated. Although a positive parental concern is strongly predictive of an underlying developmental problem, the lack of concern certainly does not imply normal development. Lack of parenting experience, cultural influences, denial, time constraints in the face of more pressing medical concerns, all contribute to parental reluctance to bring up developmental concerns...***another excellent reason to make use of a structured questionnaire that requires and elicits parental input...like the ASQ:SE.***

Valuing Parental Concerns and Input in the Screening and Surveillance Process

Parental concerns that are RED FLAGS for autism include communication concerns (e.g., not responding to name, doesn't follow directions, appears deaf at times, etc.), social concerns (doesn't smile socially, poor eye contact, in his own world, etc.), and behavioral concerns (tantrums, doesn't know how to play with toys, oversensitive to certain textures or sounds). Parents rarely complain of social delays or problems, so any and all such concerns should be immediately investigated. In addition, complaints about behavioral concerns that coexist with any other concerns of social or communication development should be immediately investigated. It is even more significant when parents voice additional concerns in the communication and behavior areas as well as in socialization. Again, the ASQ:SE seems to hold great promise in these areas.

General Developmental Screening: A Traditional Example

The **Denver Developmental Screening Test-Revised (DDST-II)** has been a *traditionally* used tool for screening in primary care. It is designed for children 0-6 years of age and it samples receptive and expressive language, articulation, fine motor-adaptive, personal-social, and gross motor skills. It yields a single score (abnormal, questionable, untestable, normal, or advanced), and can be administered and scored in 25 minutes or less. However, for as long as the tool has been around, its validity is fairly well unknown. Additionally, research has shown that the tool is significantly insensitive (meaning it missed a significant number of delayed children—true positives), and lacked specificity (meaning a significant number of normal children, true negatives, were misclassified as delayed, Glascoe, et al., 1992).

General Developmental Screening: A Better Example

The Ages & Stages Questionnaire or ASQ (Squires, et al., 1997) is an example of a good standardized developmental assessment that uses parental report for children from birth to 3 years, and provides clear drawings and directions for eliciting thoughtful responses. Separate forms of 10 to 15 items for each age range are tied to the well-child visit schedule. The tool is well-standardized and validated psychometrically, showing good sensitivity and excellent specificity, providing pass-fail scores.

Specific Screens for Autism

All professionals involved in early child care (pediatricians, neurologists, psychiatrists, psychologists, audiologists, OT, PT, etc.) should be sufficiently familiar with the signs and symptoms of autism to recognize possible indicators (social, communicative, and behavioral) of the need for further evaluation. It is important to be aware that children with autism often are referred for a variety of concerns, such as language delays, motor problems, emotional disturbance, and learning difficulties.

Specific Screens for Autism: Recent Developments

Checklist for Autism in Toddlers (CHAT, Baron-Cohen, et al., 1992, 1996) is designed to screen for autism at 18 months of age, and is also aimed at the primary care setting. The first section is 9 questions to be asked of parents, such as whether the child ever demonstrates any pretend play. The second section consists of a series of five items to be observed or administered to the child by the provider during the visit, such as seeing whether the child looks where you point (joint attention), has any interest in pretend play, or is able to follow a command. Strengths of the CHAT include its ease of administration and its demonstrated specificity to symptoms of autism in 18 month old infants.

Specific Screens for Autism: Recent Developments

In a study involving 16,000 18 month old infants, virtually all of the children failing the five item criterion on the CHAT administered twice (one month apart) were found to have Autistic Disorder when diagnosed at 20 and 42 months (Baron-Cohen, et al., 1992, 1996; Cox, et al., 1999). A proviso is that the CHAT has been shown to be less sensitive to milder symptoms of autism, as those children later diagnosed with PDDNOS and Asperger's syndrome did not routinely fail the screen at 18 months.

Specific Screens for Autism: Recent Developments

The Pervasive Developmental Disorders Screening Test-Stage 1 (PDDST; Siegel, 1998) is a clinically derived parent questionnaire, divided into three Stages, each of which is targeted at a different level of screening. The PDDST-Stage 1 is aimed for use in the primary care setting, with items aimed incrementally from birth to 36 months of age. Unlike the CHAT, this instrument rates positive as well as negative symptoms, and includes a number of questions concerning regression. Other forms of the test are for use in developmental care clinics and autism clinics. The PDDST is reported to have adequate sensitivity and specificity (Spiegel, 1999).

Screening for Autism: The ASQ: SE

We are using the ASQ: SE with parents of children ages 6 to 60 months (used in multiple programs) to monitor their child's social and emotional development. Parents complete the instrument at six-month age intervals (up to age 5), that allow for ongoing monitoring of their child's social and emotional development and growth. The instrument clearly helps parents see gaps that may be forming in their child's social and emotional development. As we know, gaps in these skill areas are often marked in children with PDD.

Screening for Autism: The ASQ: SE

Early identification and education is paramount to a parent's success. In discussion with Dr. Squires, we learned that in their testing of the ASQ: SE, they found that even though it was not their original intent, they were identifying children with significant social and emotional developmental lags who were later diagnosed with developmental disorders such as Autism. In this regard, routine utilization of this instrument in Burrell's Stay at Home Program may very well help us identify undiagnosed special needs youth in need of additional services. It will enhance early diagnostic activity. Furthermore, the instrument will be used as a significant educational tool for all parents, especially those with special needs children.

Screening for Autism: The ASQ: SE

We hope to evaluate the validity of the ASQ:SE as a screening tool in two ways:

Predictive validity—as we collect these data from ages 6 months to 3 years, we hope to conduct significant follow up with as many of these children and families as possible up to age 4 or 5. We can then examine patterns of ASQ responses at the earliest stages to determine if there is significant prediction.

Discriminant validity—we hope to collect a large number of ASQ profiles from children with established diagnoses at the various stages and from aged matched controls. We can then determine through discriminant function analysis whether the tool has satisfactory ability to classify children appropriately, and at what stage does this classification become valid.

Screening for Autism: The ASQ: SE

The ASQ-SE assesses social-emotional development between birth and age 5. Items from each stage were selected that reflect areas of frequent difficulty for children with autism and/or autism-spectrum disorders. As one reads through the items, themes begin to emerge:

- **Difficulties with interpersonal contact and interpersonal/peer relationships**
- **Problems with repetitive behaviors (otherwise known as self-stimulation, often used by autistic children to self-soothe and reduce apparent anxiety)**
- **Difficulties following directions**
- **Inattention, particularly to human faces**
- **Not engaging in common, developmentally appropriate behaviors**

Screening for Autism: The ASQ: SE

Examples from the 6-Month Evaluation:

- Does your baby smile *at* you and other family members?
(italics added)
- Does your baby like to be picked up and held?
- Does your baby stiffen and arch her back when picked up?
- When talking to your baby, does he look at you and seem to be listening?
- When awake, does your baby seem to enjoy watching or listening to people?
- Do you and your baby enjoy mealtimes together?

Screening for Autism: The ASQ: SE

Examples from 1-Year Evaluation: (in addition to the above; if phrasing has changed, the item is listed again)

- Does your baby laugh or smile at you and other family members?
- Does your baby look for you when a stranger approaches?
- Does your baby like to play games like Peekaboo?
- Is your baby interested in things around her, such as *people*, toys, and foods? (*italics added*)
- When you talk to your baby, does he turn his head, look, or smile?

Screening for Autism: The ASQ: SE

Examples from the 18-Month Evaluation:

- Does your child laugh or smile when you play with her?
- Does your child like to be hugged or cuddled?
- Does your child do things over and over and can't seem to stop? Examples are rocking, hand flapping, spinning
- When you point at something, does your child look in the direction you are pointing?
- Does your child like to play near or be with family members and friends?
- Does your child check to make sure you are near when exploring new places, such as a park or a friend's home?

Screening for Autism: The ASQ: SE

Examples from the 2-Year Evaluation:

- Does your child greet or say hello to familiar adults?
- Does your child let you know how she is feeling with either words or gestures?

Advances in the Treatment of Autism Spectrum Disorders

Evaluating and choosing among the varied treatment options is an overwhelming task for parents of children with autism spectrum disorders and the professionals who support them. Although parents and professionals who work with any young child with an established condition face similar challenges, those faced with autism spectrum disorders seem to face even greater challenges.

Advances in the Treatment of Autism Spectrum Disorders

The impact of the Internet on parents and professionals in the decision-making process is a matter of concern. The Internet now serves as a direct referral source for programs, therapies, and products. The concern is that parents may feel this information is valid even when it has not gone through a professionally based, peer review process. It is up to professionals in the field to evaluate and provide parents with the skills to assess these treatments independently (Jacobson, 2000).

Questions to Ask in Evaluating a Specific Treatment

Freeman (1997) has provided questions to ask when evaluating the adoption of a specific treatment:

- Will the treatment result in harm to the child.
- Is the treatment developmentally appropriate for the child?
- Has the treatment been validated scientifically?
- How will the treatment be integrated into the child's current program?

Questions to Ask in Evaluating a Specific Treatment

- How will the child's progress toward desired goals be evaluated?
- Is there a backup plan if the intervention is discontinued?
- Have I gotten information about this approach from a variety of sources?
- Are there less restrictive or better researched alternatives?

What Does the Research Say About Effective Components of Early Intervention?

There is substantial agreement that:

Intervention should be provided at the earliest possible age. Eligibility for programs should be determined in as time-efficient manner as possible...clearly this makes an even stronger case for the surveillance and screening systems we've been talking about.

What Does the Research Say About Effective Components of Early Intervention?

Intervention must be intensive. Lovaas (1987) described successful outcomes for 47% of the children in his study who began treatment with 40 hours of one-to-one discrete trial teaching in the home environment. This level of success has not been replicated in subsequent studies to date, but more recent research seems to support the need for at least 20-25 hours per week of systematic instruction for young children with autism (e.g., Smith & Lovaas, 1997). Intensity is not only defined as number of hours of intervention, but in terms of the duration or length of time the program is provided long term, or even as the comprehensiveness or number of elements or services provided to a child.

What Does the Research Say About Effective Components of Early Intervention?

Parent training, involvement, and support should be a key component of the program. The role of parents might range from acting as therapists or co-therapists to parents attending meetings to assist in the development of an individual family support plan or an IEP.

The curriculum should focus on the social and communication domains, as the core deficits in autism revolve around these two areas.

What Does the Research Say About Effective Components of Early Intervention?

Instruction should be systematic with individualized goals and objectives, based in the principles of applied behavior analysis (ABA).

Particular emphasis should be put on teaching for generalization of acquired skills to home or community settings. Strategies to increase generalization include using naturally occurring reinforcers, and training across settings.

Guarded, But Improving Outcomes...

Lovaas found good outcomes among 47% of his sample receiving intensive, early, behaviorally based intervention. More recent research supports gains in intellectual functioning, but not at the level Lovaas reported. Eikeseth, et al. (2002) found that children who received behaviorally based intervention made more progress than children who received a more eclectic approach. However, the authors did report that the implementers of the behaviorally based treatment received more supervision than those in the other group, which may have contributed to the results.

Guarded, But Improving Outcomes...

Smith (1999) analyzed 12 peer reviewed outcome studies, which focused on early intervention for children with autism. Nine of these were behavioral programs and 3 were from other types of programs. The mean gains in IQ were higher in the behavioral programs than in the others, ranging from 7 to 28 points in the behavioral programs, and from 3 to 9 points in the other three studies.

Guarded, But Improving Outcomes...

Unfortunately, the research that has been undertaken to evaluate the effectiveness of programs for young children with autism has generally used small sample sizes and has had inadequate controls...many studies have used outcome measures in the area of cognition and have not measured growth in social interaction and communication. Although treatment outcome research is difficult to implement, future efforts must include more of these types of outcome measures with larger groups of children.